

116TH CONGRESS
1ST SESSION

H. R. 320

To expand and enhance existing adult day programs for younger people with neurological diseases or conditions (such as multiple sclerosis, Parkinson’s disease, traumatic brain injury, or other similar diseases or conditions) to support and improve access to respite services for family caregivers who are taking care of such people, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

JANUARY 8, 2019

Ms. LEE of California introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To expand and enhance existing adult day programs for younger people with neurological diseases or conditions (such as multiple sclerosis, Parkinson’s disease, traumatic brain injury, or other similar diseases or conditions) to support and improve access to respite services for family caregivers who are taking care of such people, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Adult Day Center En-
5 hancement Act”.

1 **SEC. 2. FINDINGS.**

2 The Congress finds the following:

3 (1) One in 6 people in the United States lives
4 with a neurological disease or condition that can
5 often result in disability, and which may require the
6 individual to seek assistance in carrying out the ac-
7 tivities of daily living. Neurological diseases or condi-
8 tions such as multiple sclerosis (MS), early-onset
9 Parkinson's disease, and traumatic brain injury
10 (TBI) can also typically affect younger adults in the
11 middle of their lives.

12 (2) Multiple sclerosis is a chronic, often dis-
13 abling disease that attacks the central nervous sys-
14 tem with symptoms ranging from numbness in limbs
15 to paralysis and loss of vision. Most people with MS
16 are diagnosed between the ages of 20 and 50 years
17 of age. MS is a leading cause of disability in young
18 adults. Persons living with MS who experience more
19 severe forms of the disease are likely to require ei-
20 ther home care or nursing home placement, though
21 the vast majority would prefer to remain at home to
22 receive the care they need. Where home care is con-
23 cerned, approximately 80 percent of such care is
24 provided by unpaid caregivers who are generally
25 family members.

1 (3) Parkinson’s disease is a chronic, progressive
2 neurological disease. The four primary symptoms of
3 Parkinson’s disease are tremor, or trembling in
4 hands, arms, legs, jaw, and face; rigidity, or stiffness
5 of the limbs and trunk; bradykinesia, or slowness of
6 movement; and postural instability, or impaired bal-
7 ance and coordination. Other symptoms may include
8 cognitive changes; difficulty in swallowing, chewing,
9 and speaking; urinary problems or constipation; skin
10 problems; and sleep disruptions. As these symptoms
11 become more pronounced, patients may have dif-
12 ficulty walking, talking, or completing other simple
13 tasks. It is estimated that nearly 1,000,000,000
14 Americans will be living with Parkinson’s by 2020
15 and of those 5 to 10 percent are diagnosed younger
16 than 50 and deemed “early-onset”.

17 (4) Traumatic brain injury is a neurological
18 condition that typically results from a blow or jolt to
19 the head or a penetrating head injury and that can
20 impact one or more parts of the brain, thereby tem-
21 porarily or permanently disrupting normal brain
22 function. The Centers for Disease Control and Pre-
23 vention estimates that 153 Americans die from TBI
24 every day, and that TBIs contribute to approxi-
25 mately 30 percent of all injury deaths. Traumatic

1 brain injury is also a serious issue that affects mili-
2 tary servicemembers. Estimates in prior military
3 conflicts indicate that TBI was present in 14–20
4 percent of surviving casualties.

5 (5) Family caregivers are a crucial source of
6 support and assistance for individuals suffering with
7 disabilities. Family caregivers, the majority of whom
8 are women, provide an estimated \$470,000,000,000
9 in “free” services annually. The supply of family
10 caregivers is unlikely to keep pace with future de-
11 mand. The caregiver support ratio of potential care-
12 givers aged 45 to 64 for each person aged 80 and
13 older, for instance, is 7 to 1 in 2010, 4 to 1 in 2030,
14 and 3 to 1 in 2050.

15 (6) The majority of family caregivers (or 53
16 percent) are caring for someone ages 18 to 74.
17 Forty-seven percent of family caregivers are caring
18 for someone 75 or older.

19 (7) Adult day programs can offer services, in-
20 cluding medical care, rehabilitation therapies, dig-
21 nified assistance with the activities of daily living,
22 nutrition therapy, health monitoring, social inter-
23 action, stimulating activities, and transportation to
24 seniors, people with disabilities, and younger adults
25 with chronic diseases.

1 (8) Adult day programs geared toward people
2 living with neurological diseases or conditions such
3 as MS, Parkinson’s disease, TBI, or other similar
4 diseases or conditions provide an important response
5 to the needs of people living with these conditions
6 and their family caregivers. Adult day programs can
7 help to ameliorate symptoms, reduce dependency,
8 provide important socialization opportunities, and
9 maintain quality of life.

10 (9) Adult day programs have been shown to
11 provide a range of documented benefits including
12 improvements in functional status, social support,
13 and reductions in fatigue, depression and pain.
14 Adult day programs also reduce ongoing medical
15 care and hospital costs and decrease admissions to
16 nursing home facilities, which can be costly for many
17 families, by allowing individuals to receive health
18 and social services while continuing to live at home.

19 (10) There are currently few adult day pro-
20 grams focused on younger adult populations in the
21 United States. Although young people living with
22 neurological diseases or conditions may be able to
23 access existing adult day programs, such programs
24 are not typically intended for younger adults living
25 with chronic diseases or conditions, and may not

1 provide the appropriate services to meet the age-re-
2 lated or disability status of these individuals.

3 **SEC. 3. ESTABLISHMENT OF ADULT DAY PROGRAMS.**

4 (a) SURVEY OF EXISTING ADULT DAY PROGRAMS.—

5 (1) IN GENERAL.—Not later than 90 days after
6 the date of the enactment of this section, the Assist-
7 ant Secretary for Aging shall initiate a comprehen-
8 sive survey of current adult day programs that pro-
9 vide care and support to individuals including young
10 adults living with neurological diseases or conditions
11 such as multiple sclerosis, Parkinson’s disease, trau-
12 matic brain injury, or any similar disease or condi-
13 tion.

14 (2) SURVEY ELEMENTS.—In carrying out the
15 survey under paragraph (1), the Assistant Secretary
16 for Aging may utilize existing publicly available re-
17 search on adult day programs, and shall—

18 (A) identify ongoing successful adult day
19 programs, including by providing a brief de-
20 scription of how such programs were initially
21 established and funded;

22 (B) identify which adult day programs are
23 serving young adults living with neurological
24 diseases or conditions;

(C) develop a set of best practices to help guide the establishment and replication of additional successful adult day programs, including—

(i) program guidelines;

(ii) recommendations on the scope of services that should be provided to individuals with neurological diseases or conditions including young adults (which may include rehabilitation therapy, psychosocial support, social stimulation and interaction, and spiritual, educational, or other such services); and

(iii) performance goals and indicators to measure and analyze the outcomes generated by the services provided and to evaluate the overall success of the program; and

(D) evaluate the extent to which the Administration for Community Living supports adult day programs, either directly or indirectly, through current Federal grant programs.

(3) REPORT.—Not later than 180 days after initiating the survey under paragraph (1), the Assistant Secretary for Aging shall produce and make

1 publicly available a summary report on the results of
2 the survey. Such report shall include each of the ele-
3 ments described in paragraph (2).

4 (b) ESTABLISHMENT OF GRANT PROGRAM.—

5 (1) IN GENERAL.—Not later than 90 days after
6 producing the report required by subsection (a)(3),
7 the Assistant Secretary for Aging shall establish
8 within the Administration for Community Living a
9 competitive grant program for awarding grants an-
10 nually to eligible entities, based on the best practices
11 developed under subsection (a), to fund adult day
12 programs serving younger people with neurological
13 diseases or conditions.

14 (2) ELIGIBLE ENTITIES.—In order to be eligi-
15 ble for a grant under this subsection, an entity shall
16 demonstrate the following:

17 (A) Understanding of the special needs of
18 younger people living with neurological diseases
19 or conditions such as multiple sclerosis, Parkin-
20 son's disease, traumatic brain injury, or other
21 similar diseases or conditions, including their
22 functional abilities and the potential complica-
23 tions across all types of cases and stages of
24 such diseases or conditions.

1 (B) Understanding of the issues experi-
2 enced by family caregivers who assist a family
3 member with neurological diseases or conditions
4 such as multiple sclerosis, Parkinson's disease,
5 traumatic brain injury, or other similar diseases
6 or conditions.

7 (C) A capacity to provide the services rec-
8 ommended by the best practices developed
9 under subsection (a).

10 (3) ADDITIONAL SELECTION REQUIREMENT.—

11 The Assistant Secretary for Aging shall not award
12 a grant to an entity under this subsection if the
13 amount of the award would constitute more than 40
14 percent of the operating budget of the entity in the
15 fiscal year for which funds for the grant are author-
16 ized to be expended. For purposes of this subsection,
17 the fair market value of annual in-kind contributions
18 of equipment or services shall be considered as part
19 of the operating budget of the entity.

20 (4) SELECTION OF GRANT RECIPIENTS.—Not

21 later than 90 days after establishing the grant pro-
22 gram under this subsection, the Assistant Secretary
23 for Aging shall award the first annual series of
24 grants under the program. In awarding grants under
25 this subsection, the Assistant Secretary should en-

1 sure, to the extent practicable, a diverse geographic
2 representation among grant recipients and that, sub-
3 ject to the availability of appropriations—

4 (A) a minimum of 5 entities are selected as
5 grant recipients for the first fiscal year for
6 which such grants are awarded;

7 (B) a minimum of 10 entities are selected
8 as grant recipients for the second such fiscal
9 year;

10 (C) a minimum of 12 entities are selected
11 as grant recipients for the third such fiscal
12 year; and

13 (D) a minimum of 15 entities are selected
14 as grant recipients for the fourth such fiscal
15 year.

16 (5) REPORT.—No later than 1 year after the
17 initial award of grants under this subsection, and
18 annually thereafter, the Assistant Secretary for
19 Aging shall produce and make publicly available a
20 brief summary report on the grant program under
21 this section. Each such report shall include the fol-
22 lowing:

23 (A) A description of the adult day pro-
24 grams receiving funding under this section, in-

cluding the amount of Federal funding awarded
and the expected outcomes of each program.

(B) A description of performance goals and
indicators to monitor the progress of grant re-
cipients in—

(i) responding to the needs of younger
individuals living with neurological diseases
or conditions such as multiple sclerosis,
Parkinson’s disease, traumatic brain in-
jury, or other similar diseases or condi-
tions; and

(ii) assisting the family caregivers of
such individuals.

(C) Any plans for improving oversight and
management of the grant program.

(c) DEFINITIONS.—In this Act:

(1) The term “adult day program” means a
program that provides comprehensive and effective
care and support services to individuals living with
neurological diseases or conditions such as multiple
sclerosis, Parkinson’s disease, traumatic brain in-
jury, or other similar diseases or conditions that
may result in a functional or degenerative disability
and to their family caregivers and that may assist
participants in ways that—

1 (A) maintain or improve their functional
2 abilities, or otherwise help them adjust to their
3 changing functional abilities;

4 (B) prevent the onset of complications as-
5 sociated with severe forms of the disease or con-
6 dition;

7 (C) promote alternatives to placement in
8 nursing homes;

9 (D) reduce the strain on family caregivers
10 taking care of a family member living with such
11 diseases or conditions;

12 (E) focus on supporting the emotional, so-
13 cial, and intellectual needs of a younger adult
14 population; or

15 (F) address the needs of veterans living
16 with such diseases or conditions.

17 (2) The term “family caregiver” means a family
18 member or foster parent who provides unpaid assist-
19 ance (which may include in-home monitoring, man-
20 agement, supervision, care and treatment, or other
21 similar assistance) to another adult family member
22 with a special need.

23 (d) AUTHORIZATION OF APPROPRIATIONS.—To carry
24 out this section, in addition to amounts otherwise made
25 available for such purpose, there are authorized to be ap-

1 appropriated, and to remain available until expended, the fol-
2 lowing:

- 3 (1) \$1,000,000 for fiscal year 2019.
- 4 (2) \$3,000,000 for fiscal year 2020.
- 5 (3) \$6,000,000 for fiscal year 2021.
- 6 (4) \$8,000,000 for fiscal year 2022.
- 7 (5) \$10,000,000 for fiscal year 2023.

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